A Model for Today and Tomorrow

A Proposal for Idaho State School and Hospital and Idaho's Community-Based Service System for People with Developmental Disabilities

November, 1999

INTRODUCTION

The State of Idaho is currently faced with some critical financial and policy decisions that will determine the future of services for people with developmental disabilities for the next 40 years. These choices are not easy. They are constrained by past commitments and changing philosophies. They are filled with emotion. They have the potential to pit parent against parent and provider against consumer. But the choices must be made and, hopefully, they will reflect what is **best** for individual Idahoans with developmental disabilities, not just what is easiest or most convenient.

Idaho's system of providing services to people with developmental disabilities is in evolution. It has changed from one centered in a large custodial institution to one of various types and locations. The clientele has also changed. Many people with disabilities are not living more independently and speaking out for themselves. But some remain in institutions, including a growing number of people with both mental illness and mental retardation, some of whom are considered dangerous and aggressive. Currently in Idaho some of those with dangerous behavior are housed in unsafe and deteriorating conditions at Idaho State School and Hospital, very near those who are most vulnerable. This situation cannot continue.

What is the answer? Members of the Consortium of Idahoans with Disabilities (CID), together with representatives of the ICF/MR industry, targeted case managers, in-home services and supported living providers, and developmental disability agencies, propose a solution that combines best practice with the realities of the current environment in Idaho. We believe the proposal to be forward thinking, fair, and cost effective. The details are found in the following sections, but the essential elements of the proposal are:

1) Create safe environments where children and adults with disabilities who are vulnerable can receive quality services without being exposed to danger and harm from others

2) Develop a unified community-based system that provides a spectrum of services (including crisis services) across all parts of the state

3) Surround each person with a developmental disability with a team of friends and caregivers that supports him/her in the community setting of his/her choice

4) Create a system which compensates provides commensurate with the needs of the individuals they serve.

5) Recruit, train, and fairly compensate direct care staff to assure safe and responsible services and minimize turnover

6) Fully utilize the variety of funding methods and sources to maximize individualized services

7) Increase awareness and education to enable communities to accept and include people with development disabilities

8) Implement methods of collecting data and measuring quality of services that are useful but not burdensome

THE PROPOSAL:
A MODEL FOR TODAY AND TOMORROW

BACKGROUND

Although Idaho has an array of services across the state, these fall well short of functioning as a system. The State has chosen to privatize most of the services to adults and children with developmental disabilities. As a result, we have seen the development of a variety of private agencies who are providing different Medicaid-funded services, particularly in the more urban areas. Some of the agencies provide an array of services while others specialize in one type of service. Training for direct care staff is not standardized or required. Pay for direct care givers is low and turnover is high. Reimbursement to provider agencies does not necessarily reflect the difficulty or scope of the work. Lack of communication and cooperation among different types of providers are barriers to their operating as a system. All of this has a significant impact on the lives of Idahoans with disabilities. As the monitor and funding source for these services, the state has the opportunity and responsibility to facilitate and support the transformation of this array of providers into a seamless and smoothly working system of services and supports for people with disabilities.

Currently adults and children with developmental disabilities may receive residential services in their own homes or in the home of a caregiver or family member, or they may live in an Intermediate Care Facility for the Mentally Retarded (ICF/MR). There are currently 61 private ICFs/MR in Idaho serving over 500 individuals. There is one state-operated ICF/MR, Idaho State School and Hospital (ISSH) which currently provides services to 113 people.

People who do not reside in a facility but who are eligible for institutional care may be receiving services paid for by Medicaid through a Home and Community Based Services (HCBS) waiver. There are currently four different waivers for adults in Idaho: one for people with developmental disabilities, one for people who have been discharged from ISSH, one for people with a traumatic brain injury, and one for people with physical disabilities and the elderly. There is one waiver for children, the Home Care for Certain Disabled Children or "Katie Beckett" waiver which provides assistance

to families who opt to care for their child with significant disabilities at home. This waiver and the first two adult waivers require people to be eligible for ICF/MR level of care. As of August, there were approximately 483 people with developmental disabilities receiving services through the HCBS/DD waiver with another 35 applications pending. As of the same date, there were 42 people being served through the ISSH waiver with two applications pending. About 20 children receive services through the Katie Beckett waiver. A recent change has been made to enable young people between the ages of 18 and 21 to receive waiver services as they transition from Katie Beckett to adult HCBS waiver services. Another positive change allows people eligible for "ISSH level of care" to access that waiver without having to first be admitted and discharged from the institution. This allows them to receive home-based care that may be more costly than private ICF/MR care but less costly than ISSH care. The services that people can receive through a waiver are listed in **Appendix A.**

A UNIFIED COMMUNITY-BASED SYSTEM –

To change from the fragmented arrangement of services that currently exist, we propose the following:

✓ **EMERGENCY PLACEMENTS** - The Department of Health and Welfare should require each regional office to secure a sufficient number of "beds" that could be used for crisis placement for a person with a developmental disability. Regional need would dictate their number and location. These beds could be in homes or facilities, although one or more may require a secure setting such as might be provided in a psychiatric unit. Some of these beds may also be used for emergency respite for either adults or children with disabilities.

In conjunction with the crisis teams (see below), these beds would provide a safety net and be used instead of ISSH for emergency placements. They could also be used for diagnostic and evaluation purposes. Stays would be limited to 30 days or less. The Department of Health and Welfare is currently demonstrating a similar approach in Region II (Lewiston/Moscow/Grangeville).

✓ **CRISIS NETWORK** - The current staff expertise available at ISSH should be combined with other DHW regional staff and private sector contract personnel to provide a network of professional teams. These teams would be available at the regional or multi-regional level to provide on-site technical assistance and support to prevent the removal of a person from a home or facility during a time of crisis. In the event the person would require placement in a crisis bed, the team would work with other regional staff, providers and families to stabilize the situation and return the person to his/her home as quickly as possible. If return to the previous placement is not possible, the network would be responsible for developing a new placement with adequate services in the region. These teams could also serve as a training resource.

✓ **PROVIDER TRAINING** - Training for direct services staff, many of whom currently have little or no training, would be required. This training could be offered

through the post-secondary system and could be coordinated by the Idaho Center on Disabilities and Human Development, Idaho's University Affiliated Program at the U of I. One of the responsibilities of this program is training in the disability field. The curriculum could be one of several in use across the U.S. or a combination of these. Distance learning such as teleconferencing, self-teaching using CD or videos with written guides, or classes via the Internet would help reach remote areas and staff who cannot get away from their work to attend training. The crisis teams could also provide "roving" workshops within the regions.

The Department of Health and Welfare is conducting a week-long training for direct care staff in Region V (Twin Falls) in November using a model from Oregon. This may be the basis for or a component of an ongoing training curriculum.

✓ NEEDS-BASED REIMBURSEMENT – In order for current and future private agencies and individuals to provide the services needed by adults and children with more complex medical needs, payment must reflect the different levels of care needed. Modifications to current facility standards and creation of waiver alternatives should be developed. If a person needs fewer, more routine services, payment would be less than for someone who requires a range of specialized or unique services. Our current system of waivers for adults would require modification and additional flexibility. Not long ago, the ICF/MR industry was successful in securing a prospective reimbursement system, but this does not accommodate additional payment for additional services needed by those with significant needs. Further rate modification would need to be negotiated between ***all*** providers, consumers, and the state, but payment for these services also requires the support of policymakers such as legislators and the Governor.

✓ MODIFICATIONS TO IDAHO'S WAIVERS – Idaho would need to modify the implementation of its waiver services to remove barriers to service delivery and simplify billing procedures. DHW rules and payment policies impose limits on the amounts available and the settings in which they can be provided. The HCBS waivers for people with developmental disabilities in Idaho pay for 12 different services. In addition to these services, there are other services that are available and paid for by Medicaid as part of the Medicaid state plan.

Services under a waiver must cost no more, on average, than services would in an ICF/MR. For many people who need fewer services the cost is considerably less. There is also less regulation under the waiver. Providing services through a waiver also allows the state to capture a 70% federal Medicaid match. This is particularly relevant for individuals who have previously lived in residential care or adult foster homes, both of which are paid for entirely with state general fund dollars.

Idaho is currently phasing in the use of an HCBS waiver for people with physical disabilities and the elderly. The lessons learned through this process regarding such things as the use of fiscal intermediaries to assist people with disabilities in managing and paying for their services will be extremely helpful in determining what modifications are needed for the other waivers. In addition, some of the methods used to approve, monitor, and pay for services in Idaho do not require statutory change but can be accomplished through policies internal to the Department of Health and Welfare.

HCBS waivers should be utilized to serve children as well as adults. Although children currently receive a variety of services through the Early Periodic Screening Diagnosis and Treatment (EPSDT) program, a Medicaid waiver would provide needed flexibility and additional specialized services to children.

✓ TRANSITION FROM ISSH TO COMMUNITIES - The Department of Health and Welfare would accept no further admissions to Idaho State School and Hospital of those persons categorized as having severe or profound mental retardation or complex medical needs. Since admissions from these two population groups have been on the decline (eleven admissions in 1998-99 compared to 33 people discharged), this is can be done if we develop the other components above. Even the Department's figures show a projection of decreasing this group by 45% by 2002.

To accommodate this admission ban and accelerate movement to the community, individual treatment teams of ISSH staff, community providers, service coordinators and others would work with the person with a disability and his/her family to transition to the community setting *of their choice*. A key element of this process is that *no one* would be placed in a setting where they do not want to be. This may mean trial stays and/or the development of new alternatives. Although this transition is primarily designed to assist those with severe mental retardation or medical needs, it would also be available to any ISSH resident who wanted to and could live in the community. All individuals who are not a danger to the community would be transferred from ISSH to a home or other community setting as soon as the quality and safety of services meet the needs of the individual. Staff and funding for the State School would decrease commensurate with the decreased census. These funds would "follow the residents" to their new placements.

This plan for transitioning to community settings would also help the state avoid future problems resulting from the Supreme Court decision in Olmstead.

✓ MONITORING AND QUALITY ASSURANCE – Idaho needs to adopt and use revised methods of evaluating programs and services that assure not only safety and other standards, but also assure quality from the perspective of the person served and/or their family or guardian. Considerable monitoring procedures are already in place for facilities in Idaho. Many of these are left over from the medical model of care and although they may be necessary, they do not address customer satisfaction. As more people with significant disabilities move into the community, it is not only important to protect their health and safety, but to determine if they are getting what they need. This may require either modification to the current system of service coordination, additional training and support for adult protection workers, or a new type of "ombudsperson" who protects the person's individual rights.

Utilize the Department's oversight authority to assure quality community placements rather than imposing restrictions that result in placements at ISSH.

✓ MEDICAL SERVICES – Some residents of ISSH require a high level of services related to complex and ongoing medical needs. For these individuals to be served safely in the community, our current methods of providing medically related services in community settings must be improved. Changing to a needs-based

reimbursement system would enable community-based providers to develop these services. Development of more flexible state nursing rules and standards for delegation of tasks is also needed. Flexibility in community-based services would allow Medicaid payment to direct service staff to accompany individuals to acute care settings, including hospital stays. Realistic wages for direct service staff who need higher levels of knowledge and competence. Children whose medical needs exceed those of ISSH residents are currently receiving home-based medical services through the private duty nursing program.

✓ **PUBLIC EDUCATION AND AWARENESS** - An ongoing public awareness campaign will be conducted collaboratively between public agencies and the private sector that will increase general understanding and acceptance of people with significant disabilities. Many organizations already spend considerable time and effort in this area. Those efforts will be more effective as they are better coordinated and involve more people and groups. The strongest public education tool of all is the example set by people with disabilities living and working in communities and neighborhoods across Idaho.

THE FORENSIC PROGRAM –

Currently there are 113 residents at the Idaho State School and Hospital. Of these, 48 are regarded by the institution as "dangerous/aggressive" *(Idaho State School and Hospital, handout for the Interim Legislative Committee, September 28, 1999).* These individuals have a wide range of assaultive behaviors, have often failed in other placements, and pose a potential risk to the community. Virtually all also have a psychiatric disorder (dual diagnosis) and most are men under the age of 35 *(Idaho State School and Hospital Campus Study, December 1998).* Currently at ISSH, some of the populations are mixed, creating the potential for victimization of the more vulnerable residents.

This population is on the increase at ISSH. From the 48 today, the administration projects a rise to 78 by mid-2002 given the current treatment system. At the same time, the two other groups of residents at ISSH, those with severe or profound mental retardation or those with complex medical needs, are expected to continue to decrease 45% in the same period. Even if new buildings with better alarm systems were in use, there would still be the potential for mixing populations. All residents are allowed and required to leave their buildings to use the other campus facilities (pool, canteen, gym, work areas). This poses a potential risk to the more vulnerable populations.

Clearly, steps must be taken to separate these populations. The previous section of this proposal outlines recommendations for a smooth transition, over time, of people with severe and profound retardation and complex medical problems to community settings. In the meantime, a plan must be developed for the other residents.

THE ALTERNATIVE

We must distinguish between people who exhibit aggressive behavior (such as temper tantrums) in the residential setting and who, without adequate management, may pose a risk to staff or to other residents in their living area, and those who are capable of eluding staff, planning and executing a criminal act against members of the community at large.

The first group poses challenges to the facility or program providing residential care, but does not pose a significant risk to the community in which they live. Community providers (both ICF/MR and HCBS Waiver providers) are ready and willing to provide care and supervision for these residents, if there is adequate flexibility and reimbursement for to them to do so. This could be accomplished at the same or lower cost than ISSH. To move these residents to the community, and keep them from becoming referrals to ISSH, we need only to adopt the suggestions for needs based reimbursement and flexibility in services outlined above.

It is also necessary to change the behavior and attitude of Department personnel in terms of survey practices and delays in responding to requests for intensive services. Community-based service providers all can relate experiences when they were willing and able to deal with aggressive behaviors, but were stopped by denials of reimbursement, survey teams who instructed them to send the resident to ISSH or risk decertification, or delays in approving requests for crisis services followed by coupled with suggestions that they send the person to ISSH if they could not wait for the approvals. In this way Department staff have helped to create the emergencies which led to "emergency" placements, and in some cases, to the referrals of some residents to law enforcement or the courts.

The second group of residents in this category pose a risk to the community in which they live and require secure facilities similar to those found in our correctional system. Some of these people have serious mental illnesses and may have little or no intellectual impairment. In the past, when such individuals came into the Department's custody though the courts they were usually evaluated through one or more of the components of the private or public mental health system. Some of the recent referrals to ISSH do not meet the standard criteria for a diagnosis of mental retardation, but do have significant mental illness diagnoses. It is more reasonable to use the expertise of the Department to assist the mental health system to provide adequate evaluation and treatment for these people than to build new buildings at the State School to evaluate and treat mental illness.

Some of these residents are intellectually competent to stand trial and are legally responsible for their crimes. These people should be the responsibility of the Department of Corrections. If they have diagnoses which require and can benefit from treatment, it should be provided by the Correctional system. If the Correctional system is inadequate to meet these needs we must correct these deficiencies. If we try to transform an ICF/MR or a psychiatric facility to serve the purposes of a correctional

facility we will fail in our responsibility to provide treatment to those who are not a threat to society or we will fail in attaining the security and protection for society for which correctional facilities are designed. For these inmates we must improve the Security Medical Facility (at the Idaho State Correctional Facility inn Boise) or create a specialized correctional facility if current facilities are inadequate.

Adolescents who pose a risk to society because they have committed acts of a criminal nature (the residents of Building Six) should be treated in the Department of Juvenile Corrections. DJC is implementing an aggressive program to build treatment facilities for juveniles with mental and emotional disorders who have traditionally been housed in out-of-state facilities and they are also developing treatment programs for juvenile sex offenders. It makes sense for DJC to find a place in their programs to treat children with very mild or borderline developmental disabilities as a secondary diagnosis. DJC is in the process of building a new facility on the grounds of ISSH. This unit should be able to take advantage of the expertise available there and include a program for dually diagnosed children in this category.

We do not currently have sufficient detailed information to say at this point whether these measures could adequately address the need for placements for all of these residents and potential future referrals. If we transform the professional staff at ISSH into the crisis network, they could serve as part of the new community based "safety net". Even so, there may remain a small number of people with developmental disabilities who cannot otherwise be served. A much smaller facility with a capacity of twenty or so beds would meet this need. This facility could be public or private and could be located on the grounds of ISSH or elsewhere.

This approach could be implemented immediately and could achieve most of these goals in less time than it would take to build the proposed buildings. We could begin to move people out of the current inadequate facilities much sooner and we would have less need to mix populations as the number of admissions of aggressive residents rises while the new buildings are being financed and constructed.

THE COST

TREATMENT COSTS

For many years, it has been widely held that the costs of services at ISSH are significantly greater than the costs of services provided in smaller private facilities or homes in communities. Even as the institution downsized, the condition and age of many of the buildings created high overhead costs. During the 1999 legislative session, a presentation by the Consortium of Idahoans with Disabilities (CID) stated that the daily cost for services to a person at ISSH was $437, compared to approximately $210/day in private ICFs/MR, and around $70-105/day for services under the HCBS/DD waiver. (Current costs are somewhat different) No cost comparison was done for individuals on the ISSH waiver. These would undoubtedly be higher than the other waivers.

More recently, we have heard from DHW administrators that the high cost of care at ISSH is attributable to the array of services that the institution provides over and above that which is provided in community settings. **Appendix B** illustrates the institution's cost breakdown between "ICF/MR active treatment" services (Column 2) and those additional services (Column 3). For a comparison to be fair, the Department asserts that the figures in Column 2 should be used to compare with active treatment services in other settings.

Our research, however, provides a different perspective. **Appendix C** outlines the costs at ISSH over the past three years. The source of this data is the institution's annual reports and their final audits. While these figures show the "pure ICF/MR active treatment" costs to be $285 - $305/person/day (over the 3-year period), the additional costs appear to be based not on additional medical, pharmacy or treatment services, but reflect facility, property, and administrative costs. Based on these figures, the daily cost per person in Fiscal Year 1999, was **$453.24**. When non-reimburseable costs are added, the daily rate climbs to **$518.85.**

In a review of the same reports for private ICF-MR providers, the daily costs range from $120.29 to $251.30 *(Summary Listing of Current Long Term Care Medicaid Rates for ICF/MR Facilities, October 1, 1999)* for an average daily cost per person of **$195.59**. This represents a daily savings of $257.65 per person. Savings may be even greater in other home-based settings using a combination of waiver services.

PROPERTY COSTS

After touring Idaho State School and Hospital, it is not difficult to see why the Department of Health and Welfare is proposing to construct 4 new residential buildings. Both Building Six and Staff House, in particular, are in deteriorating condition and pose a hazard to both residents and staff. The mix of populations adds to the risk and the demand for change. We agree that the conditions under which many of the

residents of the State School are living are unacceptable. But given the increasing costs, the changing demographics, and the flexibility of funding, we see a different solution.

We propose that the development of a comprehensive community-based system could, in many cases, forestall the need for new buildings. And should that system still require a secure facility, that facility could be much smaller than that which is proposed.

The cost of the Department's construction proposal is $13,500,000. Financed over 25 years, the new buildings will cost $24,870,544. With an interest rate of 5.5%, annual loan payments will be approximately $994,824. Based on the Department's projections for the number of individuals who may reside in these buildings (78 by July 2002), the cost would be $34.94 for these residents. Apportioned over the total ISSH population (based on the current census), it would be $24.97/person/day. This is in addition to the daily treatment costs outlined above. Even if the new buildings result in an estimated maintenance savings of $110,000/year, that would have an impact of less than $3.00/day/person (based on FY 99 patient days). When these costs are added to the FY 99 daily figure of $518.85, the daily cost per person is **$540.82**. This translates into **$197,399/person** each year.

Currently the highest level of property costs allowable for private ICFs/MR is $12.74/day/person. Since that figure only applies to newer facilities, for most providers it is less. If the 78 individuals who would potentially be placed in the new buildings at ISSH, were to instead be placed in private ICFs/MR, the minimum savings annually on property costs alone would be $632,034 (see **Appendix D**). Over the life of the loan repayment, this is a **savings to the state of over $15,800,000**. If the individuals were to reside in a supported living apartment or home and pay the rent out of their monthly disability allowance, the savings tot he state would be even more substantial.

It is true that funds generated through bonds for construction cannot be used for providing services in the community. But the cost of repaying those bonds will require general and federal funds that could be used for services. We believe that through the alternatives we have proposed, that the State will ultimately have an improved service system that will also cost less.

RELATED ISSUES

ECONOMIC IMPACT

A downsize in ISSH need not mean a loss of revenue to the Nampa area. Currently, the Department leases a number of buildings on its campus, both new construction and older structures. Staff House and Building Six could be added to that list and leased to other public agencies or private organizations. This would continue to generate income for the Department and the community. Similar to the Job Corps complex, other buildings could also be built on the grounds that would positively impact the economics of the area. Interstate access and proximity to the golf courses and the city make this area attractive for businesses and other development.

A positive impact may be felt across other areas of the state with the development of new services and programs in other regions.

CHANGES TO THE JUDICIAL SYSTEM

Residents find their way to ISSH through the courts in several ways. Some are sent for temporary placement to be evaluated for their competence to stand trial for criminal charges (I.C. §18-210 *et seq.*), some are committed to the custody of the Department of Health and Welfare through the civil commitment process (I.C. §66-401 *et seq.*), and some have been convicted or plead guilty to crimes and have been placed on probation. Some courts have made admission to a facility a condition of probation.

People committed to the Department for evaluation under Title 18 or for treatment under Title 66 are placed by the Director or his/her in any suitable facility. This placement decision is determined by the Department. When new admissions to ISSH are curtailed, the courts must be informed. The courts should be encouraged to use local resources for evaluations of competency as provided in the statute. The crisis network may be helpful in this situation as would the development of greater service capacity in the community.

In order for a person to be on probation, the court must have found that the person is **competent** to stand trail or to enter a guilty plea. **The person must have been found to have sufficient capacity to be responsible for his or her crime and have been convicted or plead guilty to the offense**. The court must have imposed a sentence and suspended it, or withheld judgement on the conviction or guilty plea. When the court creates a condition or probation, it assumes that the person should serve the sentence imposed by the court, if the conditions of the probation are not met. This does not create an obligation on the part of the Department to fulfill the terms of the probation, only on the probationer. If it is made clear to the court that admission to ISSH is not an option for the defendant, the court must choose between imposing the sentence and finding other conditions on which it will allow probation of the defendant.

Under these circumstances, there is no need to change the criminal code or the civil commitment statutes to implement this proposal.

IMPACT ON FAMILIES

The ultimate closure of ISSH in its traditional role will have a direct impact on the current residents and their families. This is particularly difficult since the families of residents who have lived at ISSH for most of their adult lives expected that ISSH would always be there. But with changing practices (that would never have been anticipated when these placements were originally made), increasing admissions of persons regarded as dangerous and aggressive, and the deteriorating physical plant, the Department has said that ISSH will no longer be a long term home for anyone. The emphasis will shift toward the diagnosis, evaluation, and short-term intensive treatment of those individuals who have behaviors that pose a risk tot he community.

This will require an individualized transition plan for each of these individuals and their families and/or guardians. This planning must focus on the needs of each person and the development of a placement in the community that can meet those needs. This highly personalized approach is detailed earlier in this proposal and is key to fulfilling the state's obligations to these families.

There is also an impact on families of young children for whom institutional placement has never been a considered option. Many of these families have chosen to keep their child at home given the supports and services that have developed in more recent years. But those services are still fragmented and often difficult to piece together. These families need the infrastructure that truly supports them in keeping their child at home. Money not spent on building new institutions can be used to build that infrastructure.

JOBS

Jobs at the State School will be impacted by this proposal but so will opportunities in the community. As has been the case in the past, staff have left the institution to become community providers for former ISSH residents. For others that has not or will not be possible. Current staff may choose to continue to work at ISSH if a smaller facility is built or may work for the Department in one of its regional programs (such as in a crisis team). People may choose to continue to work in the disability field as a private provider, particularly as the community system is expanded and enhanced. They may also have the option of working for another state agency or one of the organizations or companies that choose to locate their business on the ISSH campus.

It is important that throughout this time of transition, that state employees are recognized for their value, skills, and dedication, and that they are included in the conversations an decisions that surround this process.